

Collaborative Planning for Women's Health Research in California: Proceedings from the September 2003 Convening

Executive Summary

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About the Center for Health Improvement

The Center for Health Improvement (CHI) is an independent, nonprofit health policy center based in Sacramento, California. CHI is dedicated to improving population health and encouraging healthy behaviors. CHI uses evidence-based research as the basis for policy innovation and implementation. Since its inception in 1995, CHI has partnered with all levels of government, advocacy and community organizations, philanthropic foundations, and educators.

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Research findings drive policy discussions and decisions that affect women's lives. Despite major efforts to collect health information about the state's population, however, there remain large gaps in information about the health of women and girls in California. Identifying priorities for research activity and securing funding for this research is critical to understanding the health needs of California's women and girls and informing effective state-level policy directives.

This report outlines the proceedings of a two-day convening—"Collaborative Planning for Women's Health Research in California"—held in September 2003. Intended to foster communication and collaboration in the identification of statewide priorities for women's health research in California, this event successfully brought together a diverse group of stakeholders, including academic researchers, government agencies, non-profit and community-based organizations, and community members at large. Based on their own knowledge of current research in women's health, participants worked in small groups to propose areas of emphasis for future research, as well as related strategies, action steps, and recommendations to address these areas.

The key results of this collaborative process are reported herein. While the recommendations do not necessarily reflect national or statewide priorities that may have been developed by others, they nonetheless provide insight into perceived gaps and opportunities in the field of women's health and can be used to guide future research and program efforts. While research to address some of the identified concerns may already exist or may be underway, we hope that this report will highlight the importance of continuing and strengthening efforts to expand the knowledge base on the social determinants of women's health.

Overview of Convening

An advisory committee comprised of several California-based women's health experts guided the development of the convening agenda. In addition, advisory committee members recommended potential participants for the invitation-only event. Every effort was made to engage a group of individuals that was demographically and ethnically/racially diverse and included both traditional/academic researchers and community-based organizations.

Recognizing that the breadth of women's health research issues could not be covered in a two-day session, the advisory committee chose to focus on the social determinants of health as the lens through which participants evaluated research areas of emphasis. For the purpose of the convening, the definitions of social determinants of health were derived in part from a conceptual model from the Centers for Disease Control and Prevention's *Guide to Community Preventive Services*. While the categories of social

determinants of health naturally overlap in some cases, participants in each small group work session were encouraged to concentrate on the specific social determinant assigned to their group.

On September 24-25, 2003, approximately 50 women's health experts from around the state were convened in Oakland, California. The main objective of this two-day convening—organized in close collaboration with the California Department of Health Services, Office of Women's Health—was to identify research gaps in women's health.

The convening was unique in that traditional researchers and representatives of community-based women's health organizations were brought together to jointly identify priorities. Approximately 50 individuals attended the convening. Slightly more than half of the participants were from non-profit organizations, community-based organizations, or were community members, including several monolingual Spanish-speaking women. Close to half of the participants were traditional researchers, including those affiliated with government and universities. Convening participants were separated into small groups to identify research priorities, with each group focused on a different social determinant of health. Extensive efforts were made to ensure that each group was demographically and ethnically/racially diverse and included both trained researchers and representatives of community-based organizations.

Participants spent several hours in focused work group sessions. As discussions unfolded they identified priority areas in which more research is needed, as well as strategies, action steps, and recommendations to address the needs. Each of the six groups discussed one of the following social determinants of health, for which they were provided definitions:

1. Culture
2. Education
3. Employment
4. Health and Health Services
5. Place
6. Social Support

At the request of participants, a seventh group conducted its discussion in Spanish and focused on issues that cut across all six of the above social determinants of health. The recommendations produced by this group were later integrated into those of the small work groups and are not reported separately.

Recommendations

The full report is organized into six sections corresponding to the social determinants of health outlined above. Proposed areas of emphasis for women's health research, as well as strategies and action steps to support the recommended research priorities, are included for each social determinant of health.

Given the diversity of the convening participants and the fairly broad topics for discussion, the specific recommendations that emerged were quite varied in nature and do not lend themselves to a summary. One theme, however, was consistently evident. Participants across all groups emphasized the importance of using a community-based participatory research (CBPR) approach when conducting research on the social determinants of women's health.

Community-based participatory research (CBPR) involves community-researcher collaboration on all aspects of the research process from considering and developing the research question, to designing the methodology, participating in the research activity, analyzing the results, and disseminating the findings.

CBPR is believed to respond to several specific concerns with traditional research: community distrust of research, research that does not utilize community knowledge, research that is not returned to the community to improve community health, and research that does not empower community members to generate knowledge. For the community, CBPR ensures that research will be relevant to community needs, provides useful tools for further evaluation and research, and supports policy and programmatic changes as advocated by the community. For the researcher, CBPR supports ethical access to a community, opportunity for knowledge transfer from the community to the researcher about the community of interest, and the confidence that the research will actually be of use.

Because this theme was reflected throughout the work of each small group, we have developed a set of overarching recommendations related to CBPR. We encourage women's health advocates within public, private, and non-profit organizations to consider these methods in future efforts to collaboratively address the research priorities specified in the full convening report.

- 1. Work with community-based organizations to establish research priorities.** Collaborate with community groups to identify stakeholders who are best positioned to provide information about community research needs. Convene researchers and community-based organizations to identify populations that current surveys do not typically reach.
- 2. Regularly engage community-based organizations in conducting research.** Work with community-based organizations through all aspects of the research process, including developing research questions, collecting and analyzing data, and disseminating findings. Make data sources more accessible to community researchers for their own interpretation, analysis, and use, while ensuring the confidentiality of those on whom the research is based.
- 3. Create funding mechanisms that facilitate collaborative partnerships between community-based organizations and academic researchers.** Funding entities can take several steps to encourage community-based participatory research. For example, providing points in proposal scoring for collaborative research may

motivate academics to seek community partners. Moreover, building trust between academic researchers and community groups takes time. By structuring Requests for Proposals (RFPs) to include additional time to build these relationships, funders can help foster new partnerships between academic institutions and community-based organizations. Finally, ensuring equitable budget allocations to community-based researchers will help communities more easily participate.

- 4. Regularly disseminate research findings to communities.** Barriers to disseminating research findings to communities can result in a disconnect between theory and practice. Regular communication between academic researchers and community stakeholders should be supported through a variety of methods, such as public issue forums and newsletters. In addition, community-based research networks can be established to discuss and disseminate research findings via community forums and brief reports/newsletters.
- 5. Incorporate information on environmental factors into research protocols.** Solicit information about “place” (e.g., physical neighborhood, and social, economic and environmental factors) to which a person participating in the study is exposed. Limited attention has been paid to the effect of “place” on health behaviors and outcomes.
- 6. Incorporate evaluation or additional research into new programs. Ongoing** evaluation of new programs will help us define and support best practices. Funders can help support evaluation efforts among grantees by including project funding for evaluation.